

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research
AUTHORS	Lippiett, Kate; Richardson, Alison; Myall, Michelle; Cummings, Amanda; May, Carl

VERSION 1 – REVIEW

REVIEWER	Dr Morag Farquhar (Senior Lecturer) University of East Anglia (UEA), UK
REVIEW RETURNED	11-Feb-2018

GENERAL COMMENTS	<p>This paper reports on a systematic search and synthesis of qualitative data from papers on patient and carer experiences of burden of treatment in lung cancer and COPD. I enjoyed reading it. It is clearly written, with logical flow. The standard of the methods in the systematic search and synthesis is high and well reported (although no PRISMA checklist was available to the reviewer). The paper synthesises the growing body of work highlighting differences in the experiences of patients and carers living with cancer and COPD, despite these being two of the most common respiratory conditions in the UK, and the particular challenges of the COPD trajectory. Publication of research to improve care in COPD is welcomed and this is an interesting piece of work, however I have a few queries/points that need responding to/addressing (plus some observations).</p> <p>Major:</p> <p>1) Abstract, line 46: Either the word “consequently” is not quite the right word (or is unnecessary), or the sentence order needs swapping. It feels a leap from noting the lack of recognition or understanding of COPD to saying that workload is therefore balanced with the demands of everyday life. The sentence beginning “Consequently...” would work better following the next sentence (beginning “Treatment workload...”) as the latter provides greater explanation than in the current paragraph structure.</p> <p>2) Abstract, conclusion: “affirms” may be more appropriate than “reveals” as the latter implies this is the first time this phenomenon has been revealed. Differences in the experience of COPD and lung cancer have been revealed before.</p> <p>3) Abstract, conclusion, final sentence: I agree that a workload that exceeds capacity is a driver of treatment burden (this is clear in the literature and very clear in your analysis, but I am not convinced it is the primary driver. The literature (and also your analysis) shows that level of understanding and, perhaps more importantly, the length of the (burdensome) disease trajectory are also key drivers. I would suggest a subtle change from “the” to “a” in this sentence to “...a workload which exceeds capacity may be a driver of treatment burden” (unless level of understanding and length of disease</p>
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	<p>trajectory are part of capacity? or workload? – if so, not currently clear – e.g. could level of understanding be an informational task in relation to workload or an informational resource in relation to capacity?).</p> <p>4) Introduction, p4, line 17: this is more of a question to the authors than a review point, but it does relate to Point 3 above – is knowledge and the health system itself part of the collective level capacity?</p> <p>5) Aim of the review, p5, line 50: delete “international” as suggests unlimited, but only certain countries included (for good reasons).</p> <p>6) Aim of the review, p5, line 54: hard to say patients living with lung cancer or COPD – many have both.</p> <p>7) Methods – Identifying relevant studies, p6, line 16: unclear why this was a replication and extension of a previously developed strategy and no further reference to this other than in the PRISMA flow diagram (which was slightly confusing as it included heart failure and chronic kidney disease).</p> <p>8) Methods – Study selection and appraisal, p7, line 2: states four authors as screening citations and abstracts, but unclear if all four screened all the citations and compared their results or if each was allocated a batch to screen.</p> <p>9) Methods – Study selection and appraisal: how were any disagreements resolved (there is some reference to this in the acknowledgements but should perhaps be in the methods?)</p> <p>10) Methods: In the abstract it states that the search was conducted up to December 2015, but this is not mentioned in the methods.</p> <p>11) Methods – Data extraction and analysis, p7, line 31: status passage theory is mentioned. It may help readers to briefly explain what this relates to and why it was used.</p> <p>12) Methods – Data extraction and analysis, p7, line 37: I couldn’t follow the section of this sentence about “comparing sets” – not sure if a word is missing or if it needs rewording e.g. “sets were compared”?</p> <p>13) Methods: in the discussion a taxonomy is presented (Table 2). It is a really useful table but to me it represents findings (not discussion) and felt as though it should have been in the findings section, therefore something about how it was developed should be in the methods.</p> <p>14) Results – Characteristics of studies, p7, lines 53-54: just an observation... the COPD papers seemed to include a notably smaller proportion of informal carers to the cancer papers. This could reflect a greater heterogeneity in the disease stage within the COPD paper populations (with more patients being earlier in the trajectory and therefore not identifying a carer) or that less research has been conducted on COPD carers compared to lung cancer carers?</p> <p>15) Results – COPD as a “way of life”, p9: again, just an observation – language is key here as COPD is often described as “managed” rather than “treated”, whereas cancer is “treated”.</p> <p>16) Results – Identifying and accessing treatment options p10, lines 40-41: patients being told there is nothing more that can be done often occurs at the advanced stage of COPD – wonder if you found this and if it is worth specifying?</p> <p>17) Results – Accessing and navigating... p11, lines 18-20: not all COPD patients require specialist care (unlike most lung cancer patients) – many are managed entirely in generalist primary care. This really distinguishes much of the experiences of the two disease groups.</p> <p>18) Results – Accessing and navigating... p11, lines 27-28: the need for COPD patients to update HCPs on treatment changes reflects</p>
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	<p>Point 17 above – those COPD patients that access secondary care will also be being looked after by primary care, whereas when cancer patients move under the wings of secondary care they may not go near primary care for some time.</p> <p>19) Results – Practical workload... p12, lines 27-28: again, an observation, lung cancer patients may prioritise their treatment and rigidly adhere to it as cancer is seen by patients as more of a (immediate) threat than COPD.</p> <p>20) Results – Attitude towards treatment – Treatment as work, p12, line 44: not come across COPD being described as a “planning” disease before – rather the opposite. Patients and carers usually say the opposite (especially when disease is advanced) as they simply can’t plan due to the unpredictability of the condition (even daily). Maybe “managing” is a better word?</p> <p>21) Results – Attitude towards treatment – Treatment as a relief, p13, line 54: access to COPD services such as PR is also difficult because they are patchily provided, in contrast to cancer services. It is also a group-based intervention: some patients are reluctant to join groups.</p> <p>22) Results – Attitude towards treatment – Treatment as a relief, p14, line 7: is communication from or between HCPs, or both?</p> <p>23) Results – Attitude towards treatment – Treatment as a relief, p14, lines 31-33: a lot of COPD patients see none of these specialist services (in particular, access to day hospice is very rare in COPD), in stark contrast to lung cancer patients whose care is almost entirely specialist.</p> <p>24) Results – Capacity, p16: from here I found the heading levels confusing and hard to distinguish – may need reviewing/revisiting? (e.g. should the “Undeserving of treatment” heading on p19 be italicised? And some headings have colons, some not)</p> <p>25) Results – Capacity – Personal capacity to self-manage, p19: cancer patients can have access PR but, more importantly, they also have access to a lot of other supportive interventions and services.</p> <p>26) Results – Concealing of stigmatizing condition, p20: the lack of visibility can be due to being housebound due to breathlessness rather than concealment, or to embarrassment from being breathless or coughing in public.</p> <p>27) Results – Undeserving of treatment, p19: there is something different in the language relating cancer – words like “brave” and “battle” and “fight” get used, which are rarely applied to chronic lung disease.</p> <p>28) Results – Marked by treatment, p20, line 37: would be helpful to provide a reference(s) for the point about avoiding social situations as rather than avoidance this can also be due to breathlessness and houseboundness.</p> <p>29) Results – Social isolation – Self imposed, p21, line 46: as well as being self-imposed due to embarrassment there can be the actual effect of breathlessness preventing patients from leaving the home.</p> <p>30) Results – Social isolation – Self imposed, p21, lines 53+: I would argue that psychological co-morbidities do not self-impose social isolation – they would be better located and discussed under involuntary social isolation (also, some of that anxiety will be in relation to potentially getting breathlessness when out and about, and away from established strategies to manage it).</p> <p>31) Discussion – the developed taxonomy would sit better in the findings section.</p> <p>32) Discussion – p23, line 34: I would have liked to have seen more about how clinicians can use the taxonomy – perhaps some examples (could be in a box if word count tight?). This would also demonstrate the clinical utility of the review.</p>
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	<p>33) Discussion – p24: good to acknowledge that the results of the studies included were identified through the lenses of a range of authors, but also could add that this review was conducted through a further lens?</p> <p>34) Discussion – P24, lines 13-15: although the papers don't discuss multi-morbidity it will be there, especially in COPD where our work found patients with advanced disease from a population-based sample had a median of four other conditions. Also, a fair proportion of patients with lung cancer will also have COPD.</p> <p>35) Discussion: the search end date of December 2015 should perhaps be mentioned in the limitations section. Reviews, particularly high quality, thorough reviews like this one, take some time to complete but there could be reference to the end date being more than two years ago.</p> <p>36) Discussion – Illness as agent/patient as agent, p25, line 20: true that patients and carers can build up strategies over time, but they are not always the right strategies.</p> <p>37) Discussion – Illness as agent/patient as agent, p25, line 34: some avoid hospitalisation.</p> <p>38) Discussion – Social skill..., p26, line 2: cancer carers can also lack a choice in taking on the caring role, but the caring trajectory length is shorter.</p> <p>39) Discussion – Social skill..., p26, line 19: may not (just) be due to peers dying around them but due to the shorter trajectory meaning there is less need/seeking of peer support.</p> <p>40) Discussion – Social skill..., p26, line 26: not sure about the word "conceal" (although it is in some literature) – it is more about just getting on with life in COPD ("living with" COPD)</p> <p>41) Discussion – Social skill..., p26, line 35: not sure "attrition" of social skill and capital is the right term? Rather they have lost opportunities to use their social skill and access capital</p> <p>42) Conclusion, p26, line 46: not sure that cancer is the "most dreaded of all diseases" – certainly the most dreaded of the two diseases (COPD and cancer)</p> <p>43) Conclusion, p27, line 27: again, the statement that "a workload which exceeds capacity is likely to be the primary driver of treatment burden" somehow loses the impact of poor understanding of COPD and the differences in the disease trajectories of COPD and lung cancer. I would lean to "...a primary driver".</p> <p>44) Figure 1a: could this not be prepared for just the COPD papers? Not sure why CKD and CHF are included in the higher rows. I am not following how review papers can be "identified as primary studies" (in one of the cells). Also, no title (needs to say that it is the PRISMA for the COPD literature) and poor quality reproduction.</p> <p>45) Figure 1b: no title (needs to say that it is the PRISMA for the lung cancer literature) and poor quality reproduction.</p> <p>46) Table 1: no title.</p> <p>47) Table 2: I presume the contents of the two columns to left are from BoT theory and the two on the right are from the findings of the review? If so then the table would benefit from a top row stating this, and also inclusion of reference numbers for the relevant papers for each item. I also continue to think "Psychological co-morbidities..." should be in "Social isolation (involuntary)" rather than "Social isolation (self-imposed)" – somehow that is even clearer in this table than in the text. It also feels like the physical effects of the condition should be in the "Social isolation (involuntary)" section e.g. breathlessness resulting in houseboundness.</p> <p>Minor:</p> <p>1) Title: the term "caregiver" is used throughout the manuscript but "care giver" (two separate words) in the title – suspect this is an</p>
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	<p>oversight.</p> <p>2) Methods – Treatment..., p9, line 36: delete the hyphen?</p> <p>3) Methods – COPD as a “way of life” p9, line 54: don’t think “everyday” needs speech marks.</p> <p>4) Methods – Identifying and accessing treatment options p10, line 27: change the colon to a full stop (suspect there was once a quote here?)</p> <p>5) Results – Identifying and accessing treatment options p10, line 50: you have the word “treatment” twice in the sentence – change second one to “them”?</p> <p>6) Results – Practical workload... p12, line 4: there is a semi-colon that should be a comma</p> <p>7) Results – Attitude towards treatment – Treatment as work, p13, line 7: “are” should be “were”</p> <p>8) Results – Attitude towards treatment – Treatment as work, p13, line 12: change the colon to a full stop (suspect there was once a quote here?)</p> <p>9) Results – Attitude towards treatment – Treatment as a relief, p13, line 31: should “has” be “had” or be deleted?</p> <p>10) Results – Attitude towards treatment – Treatment as a relief, p13, line 49: “...than consulting their own preferences” may be better as “...than their own preference”</p> <p>11) Sometimes “HCP” is used, sometimes “healthcare professional”</p> <p>12) Results – Enacted stigma from healthcare professionals, p21, line 23: comma missing after “COPD” (“...COPD, experienced....”)</p>
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REVIEWER	Dr Carol Kelly Edge Hill University, Lancashire, England.
REVIEW RETURNED	19-Feb-2018

GENERAL COMMENTS	<p>This is overall an interesting review that appears to answer a relevant question. There are however a few oversights within the write up that I feel need addressing:</p> <p>The methods section is quite weak through lack of detail. Why just qualitative papers, why not mixed methods? This needs to be acknowledged with clear rationale.</p> <p>What about grey literature - included/excluded</p> <p>Quality appraisal of studies is not referred to - this is a central tenant of SR and should be covered in detail in the methods section stating what tool was used, who did the QA and how this was then incorporated into the narrative review.</p> <p>How did methods ensure the minimization of errors in regards to data extraction?</p> <p>There seem relatively few verbatim extracts for a qualitative review.</p> <p>It is usual in SR for inclusion and exclusion criteria to mirror - this is not the case here. Were other systematic reviews included?</p> <p>A full account of the search terms used should be appended, perhaps as an on-line supplement.</p> <p>I found it difficult to follow the overall theme structure and how the proposed grouping of coded data (p8) manifested in the findings. Sub-headings didn't match from the proposed structure to the theme headings. I wonder whether signposting Table 2 earlier (i.e. on p8)</p>
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	<p>would help to clarify this.</p> <p>Some themes, e.g. 'treatment as relief' seem positive, yet negative aspects were also discussed under this sub-heading, e.g. patients report hospital stay as chaotic.</p> <p>The overall narrative of papers lacks reference to quality appraisal (QA). Without the worth of individual studies' design features it is very difficult to ascertain the findings for quality. Where QA is acknowledged this is superficial and inconsistent</p> <p>Overall there are no clear recommendations for policy, practice or research.</p> <p>p7, line 31 - Regarding theoretical approaches there is a need to define 'middle-range' and 'status passage theory'. I think there is more scope to discuss how the 'framework' was constructed.</p> <p>p20, line 35 - is a reference needed for 'closed awareness context'</p> <p>p22, line 57: should be many or several conditions, not 'all'</p> <p>p23, line 9 - May et al 2016 needs Vancouver reference</p> <p>p24, line 10-14 - there is insufficient acknowledgment of limitations, e.g. no mixed methods, no non-English language etc.</p> <p>Whilst I feel this could be a valuable addition to the evidence base, the overall write- up of the review does not allow replication through the lack of search strategy details, nor does it allow assessment of quality through the dearth of reference to quality appraisal or strengths and limitations of the body of evidence included in the review.</p>
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REVIEWER	Nicola Ring School of Health and Social Care Edinburgh Napier University Edinburgh Scotland UK
REVIEW RETURNED	29-Mar-2018

GENERAL COMMENTS	<p>This paper represents an important topic internationally. I would like to see this paper published but it requires considerable revision. In particular, it needs to be clearer re: what you did to get these results and the text needs better editing & presenting.</p> <p>Editing & presenting issues: For example, the abstract refers to eligible papers being from Australia yet Table 1 refers to Australasia. Better signposting is needed for readers eg. p7 refers to JH who is not on author list so,referring readers to the acknowledgments would be useful at this point. Appendix 1 is in a tiny font which is not reader friendly. You present a lot of information with many headings/sub-headings in the main text. This breaks the flow for readers but it's also not always clear when headings are primary or secondary constructs without referring to table 2 e.g. lines 33 and 36 workload and diagnosis are different levels but the text does not differentiate these enough. This means readers are constantly flicking between the text and table to understand what's what. This is especially so the further into the text the reader gets e.g. p16 - line 17 capacity - this needs to be made explicit that this is your 2nd primary construct and how many secondary constructs follow. Other examples of where the text lacks clarity and consistency are p16 refers to enhanced capacity following diagnosis, Table 2 refers to enhanced by diagnosis but p8 definition of capacity makes no mention of diagnosis. Figure 1b needs to refer to lung cancer.</p>
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	<p>The discussion starts with strengths and limitations but again this creates a disconnect in the flow of the narrative. I would prefer your results led directly to your two final points re: illness as agent and social skill and that this info appeared before your strengths/limitations.</p> <p>Re: your methods. There are many approaches to qualitative evidence synthesis it is not clear why you decided on this approach. Your approach is novel as you use Shippee's proposition but you do not say much about this (and what you do say is in your results section). There needs to be more detail about what you did e.g. was Shippee used as the explanatory propositions were formulated or was this used later? Did you exclude any studies based on RATS? Who checked extracted data for accuracy? p6 says you replicated and extended a previous search strategy and refers readers to another paper. Detailed info about the search strategy needs included in this paper - readers should not be expected to look elsewhere for that information especially as the first search was for systematic reviews rather primary qualitative studies so you need to make it clear how your extensions here ensured you identified all relevant studies. Your limitations should also consider your QES approach e.g. you had 85 copd and 42 lung cancer studies -did the huge volume of qual data limit your ability to retain conceptual depth? Could you have done something differently e.g. perhaps synthesised the two groups of studies then brought the findings together? How did you ensure reflexivity in your study.</p>
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VERSION 1 – AUTHOR RESPONSE

REVIEWER'S COMMENTS	RESPONSE
Abstract, line 46: Either the word “consequently” is not quite the right word (or is unnecessary), or the sentence order needs swapping. It feels a leap from noting the lack of recognition or understanding of COPD to saying that workload is therefore balanced with the demands of everyday life. The sentence beginning “Consequently...” would work better following the next sentence (beginning “Treatment workload...”) as the latter provides greater explanation than in the current paragraph structure.	Thank you for this helpful comment. Amended accordingly.
Abstract, conclusion: “affirms” may be more appropriate than “reveals” as the latter implies this is the first time this phenomenon has been revealed. Differences in the experience of COPD and lung cancer have been revealed before.	Thank you for this helpful comment. Amended accordingly.
Abstract, conclusion, final sentence: I agree that a workload that exceeds capacity is a driver of treatment burden (this is clear in the literature and very clear in your	Thank you for this helpful comment. Change from definite (the) to indefinite (a) article. Your discussion of what capacity may cover is extremely pertinent. We have also given a more detailed description of capacity

analysis, but I am not convinced it is the primary driver. The literature (and also your analysis) shows that level of understanding and, perhaps more importantly, the length of the (burdensome) disease trajectory are also key drivers. I would suggest a subtle change from “the” to “a” in this sentence to “...a workload which exceeds capacity may be a driver of treatment burden” (unless level of understanding and length of disease trajectory are part of capacity? or workload? – if so, not currently clear – e.g. could level of understanding be an informational task in relation to workload or an informational resource in relation to capacity?).	in the paper in order to give the reader more conceptual clarity.
Introduction, p4, line 17: this is more of a question to the authors than a review point, but it does relate to Point 3 above – is knowledge and the health system itself part of the collective level capacity?	Thank you for this helpful discussion point. See above.
Aim of the review, p5, line 50: delete “international” as suggests unlimited, but only certain countries included (for good reasons).	Thank you for this helpful suggestion. Amended accordingly.
Aim of the review, p5, line 54: hard to say patients living with lung cancer or COPD – many have both.	We agree that many patients living with lung cancer or COPD have both conditions. However, in this review, we explicitly looked at studies that defined patients as having one or the other condition. We have made this explicitly clear in what is not included in the literature.
Methods – Identifying relevant studies, p6, line 16: unclear why this was a replication and extension of a previously developed strategy and no further reference to this other than in the PRISMA flow diagram (which was slightly confusing as it included heart failure and chronic kidney disease).	Thank you for your helpful comment. We have added further information about this in the methods section.
Methods – Study selection and appraisal, p7, line 2: states four authors as screening citations and abstracts, but unclear if all four screened all the citations and compared their results or if each was allocated a batch to screen	Thank you for this helpful comment. We have amended the methods section accordingly.
Methods – Study selection and appraisal: how were any disagreements resolved (there is some reference to this in the acknowledgements but should perhaps be in the methods?)	Thank you for this helpful comment. We have amended the methods section accordingly.
Methods: In the abstract it states that the search was conducted up to December 2015, but this is not mentioned in the methods.	Full inclusion/exclusion criteria including the fact that the search was conducted up to December 2015 are detailed in Table 1 which is signposted in the methods.
Methods – Data extraction and analysis, p7, line 31: status passage theory is mentioned.	Thank you for this helpful comment. An explanation of

It may help readers to briefly explain what this relates to and why it was used.	status passage theory has been included.
Data extraction and analysis, p7, line 37: I couldn't follow the section of this sentence about "comparing sets" – not sure if a word is missing or if it needs rewording e.g. "sets were compared"?	Thank you for pointing this out. The sentence has been reworded.
Methods: in the discussion a taxonomy is presented (Table 2). It is a really useful table but to me it represents findings (not discussion) and felt as though it should have been in the findings section, therefore something about how it was developed should be in the methods.	Thank you for pointing this out. Further detail of how the taxonomy was developed has been given in the methods.
Results – Characteristics of studies, p7, lines 53-54: just an observation... the COPD papers seemed to include a notably smaller proportion of informal carers to the cancer papers. This could reflect a greater heterogeneity in the disease stage within the COPD paper populations (with more patients being earlier in the trajectory and therefore not identifying a carer) or that less research has been conducted on COPD carers compared to lung cancer carers?	It is an interesting observation which we also noted. We have not discussed it further in the paper owing to limited word count. The observations from our follow on empirical study show that patients (almost) always bring an informal caregiver to their lung cancer consultations, whereas this happens only approximately 50% of the time in COPD consultations – this may reflect the priority both carer and patient gives to treatment in lung cancer as discussed in our paper.
COPD as a "way of life", p9: again, just an observation – language is key here as COPD is often described as "managed" rather than "treated", whereas cancer is "treated".	This is an interesting observation, which we also noted. We have not discussed it further in the paper owing to limited word count.
Identifying and accessing treatment options p10, lines 40-41: patients being told there is nothing more that can be done often occurs at the advanced stage of COPD – wonder if you found this and if it is worth specifying?	This is an interesting observation. In the papers we included, we found that being told that nothing more could be done occurred throughout the disease trajectory.
Accessing and navigating... p11, lines 18-20: not all COPD patients require specialist care (unlike most lung cancer patients) – many are managed entirely in generalist primary care. This really distinguishes much of the experiences of the two disease groups.	We agree and have amended the discussion section to make this point more clearly.
Accessing and navigating... p11, lines 27-28: the need for COPD patients to update HCPs on treatment changes reflects Point 17 above – those COPD patients that access secondary care will also be being looked after by primary care, whereas when cancer patients move under the wings of secondary care they may not go near primary care for some time.	We agree and have amended the discussion section to make this point more clearly.
Practical workload... p12, lines 27-28: again, an observation, lung cancer patients	We agree with this comment and have modified this

<p>may prioritise their treatment and rigidly adhere to it as cancer is seen by patients as more of a (immediate) threat than COPD.</p>	<p>section of the paper so that our comments explicitly reflect this.</p>
<p>Results – Attitude towards treatment – Treatment as work, p12, line 44: not come across COPD being described as a “planning” disease before – rather the opposite. Patients and carers usually say the opposite (especially when disease is advanced) as they simply can’t plan due to the unpredictability of the condition (even daily). Maybe “managing” is a better word?</p>	<p>Our findings in the papers we included were that patients explicitly and repeatedly used the verb, plan – see below, bolding ours:</p> <p>According to the participants, COPD is a planning disease. They could no longer take unplanned trips as before; instead meticulous planning was required: all the medications had to be brought along (Lindqvist & Hallberg, 2010, p.463)</p> <p>“We must always think about where to travel. We can’t just go to any environment. There’s a lot of planning. When we go somewhere, we must take a lot of medicines with us.” (Lindqvist et al, 2013, p.45)</p> <p>The majority of the women reported that they did what they wanted but experienced that everything took longer than before and that planning was essential: “Things generally take more time...I always do what I want...even if it kills me.” . (Nykqvist et al, 2013, p.376)</p> <p>“I have to plan everything. I mean, like if I go somewhere I got to make sure that I...don’t have to really walk a lot.” (Panos et al, 2013, p.337)</p> <p>“Everything is very deliberate. I plan every move before I make it because I don’t want to go back and do it again. (76 M) (Schroedl et al, 2014, p.1435)</p> <p>“Planning and thinking ahead of time is the key. Knowing my limits is essential and being smart about the activities I do. Otherwise I would end up unwell.” [Riley, aged 64] (Sossai et al, 2011, p.636)</p> <p>Planning was a key element in effect self-management and was seen as a way of preventing situations that might trigger panic attacks: “...Your</p>

	<p>whole life revolves around ‘how close will I be able to park?’ I will have to go half an hour earlier than everyone else, and then I can make sure I get a parking space. And ‘how far away from the room are the toilets?’ Things that everybody else takes for granted. (Willgoss et al, 2012, p.566)</p>
<p>Results – Attitude towards treatment – Treatment as a relief, p13, line 54: access to COPD services such as PR is also difficult because they are patchily provided, in contrast to cancer services. It is also a group-based intervention: some patients are reluctant to join groups.</p>	<p>We agree with both of these observations. However, neither of these issues came through clearly in the papers that we included. Contextual factors complicating access to PR were discussed by patients (e.g. the difficulty of getting to PR). We haven’t discussed this in our paper owing to word limit.</p>
<p>Results – Attitude towards treatment – Treatment as a relief, p14, line 7: is communication from or between HCPs, or both?</p>	<p>Thank you for this helpful comment. We meant communication from and between HCPs and have amended this accordingly.</p>
<p>Attitude towards treatment – Treatment as a relief, p14, lines 31-33: a lot of COPD patients see none of these specialist services (in particular, access to day hospice is very rare in COPD), in stark contrast to lung cancer patients whose care is almost entirely specialist.</p>	<p>We agree with this observation and have added a comment to this effect in the discussion section.</p>
<p>Capacity, p16: from here I found the heading levels confusing and hard to distinguish – may need reviewing/revisiting? (e.g. should the “Undeserving of treatment” heading on p19 be italicised? And some headings have colons, some not)</p>	<p>Thank you for this helpful observation. We have revisited the headings to align more clearly with the taxonomy. We have endeavoured to be consistent in our colonisation.</p>
<p>Personal capacity to self-manage, p19: cancer patients can have access PR but, more importantly, they also have access to a lot of other supportive interventions and services.</p>	<p>We have removed the statement re lack of cancer patients access to PR. We discuss the access of cancer patients to health care services and professionals in the discussion section.</p>
<p>Results – Concealing of stigmatizing condition, p20: the lack of visibility can be due to being housebound due to breathlessness rather than concealment, or to embarrassment from being breathless or coughing in public.</p>	<p>Thank you for this point. We discuss the decline of pathophysiological function /embarrassment as a form of social isolation later in the paper.</p>
<p>Undeserving of treatment, p19: there is something different in the language relating cancer – words like “brave” and “battle” and “fight” get used, which are rarely applied to chronic lung disease.</p>	<p>We agree and, had word count permitted, would have loved to have looked in detail at the language e.g. manage vs treat and use of fight metaphor vs blame and culpability language of COPD. Unfortunately, this is beyond the scope of this paper.</p>
<p>Marked by treatment, p20, line 37: would be helpful to provide a reference(s) for the point about avoiding social situations as</p>	<p>Thank you for pointing out the lack of references . References given.</p>

rather than avoidance this can also be due to breathlessness and houseboundness.	
Social isolation – Self imposed, p21, line 46: as well as being self-imposed due to embarrassment there can be the actual effect of breathlessness preventing patients from leaving the home.	We agree and discuss the fact that involuntary social isolation worsens with disease progression and deterioration of physical function.
Results – Social isolation – Self imposed, p21, lines 53+: I would argue that psychological co-morbidities do not self-impose social isolation – they would be better located and discussed under involuntary social isolation (also, some of that anxiety will be in relation to potentially getting breathlessness when out and about, and away from established strategies to manage it).	Thank you for this point. We have relocated psychological co-morbidities under involuntary social isolation.
Discussion – the developed taxonomy would sit better in the findings section.	Thank you for this point. We agree and have amended accordingly.
Discussion – p23, line 34: I would have liked to have seen more about how clinicians can use the taxonomy – perhaps some examples (could be in a box if word count tight?). This would also demonstrate the clinical utility of the review.	We agree that it is useful to demonstrate the clinical utility of the review. We have added a box of recommendations for clinical practice.
Discussion – p24: good to acknowledge that the results of the studies included were identified through the lenses of a range of authors, but also could add that this review was conducted through a further lens?	Thank you for this point. We agree and have amended accordingly.
Discussion – P24, lines 13-15: although the papers don't discuss multi-morbidity it will be there, especially in COPD where our work found patients with advanced disease from a population-based sample had a median of four other conditions. Also, a fair proportion of patients with lung cancer will also have COPD.	Thank you for this comment. We agree – this was implicit and has now been made explicit.
Discussion: the search end date of December 2015 should perhaps be mentioned in the limitations section. Reviews, particularly high quality, thorough reviews like this one, take some time to complete but there could be reference to the end date being more than two years ago.	Thank you for pointing this out and for your kind words about the quality of the review. We agree and have added this to the limitations section.
Discussion – Illness as agent/patient as agent, p25, line 20: true that patients and carers can build up strategies over time, but they are not always the right strategies.	We agree with this comment, but unfortunately our word count does not allow us to explore this more fully. We are exploring this concept further in our empirical study which is currently underway.
Discussion – Illness as agent/patient as	We agree and have amended this comment

agent, p25, line 34: some avoid hospitalisation.	accordingly
Discussion – Social skill..., p26, line 2: cancer carers can also lack a choice in taking on the caring role, but the caring trajectory length is shorter.	We agree and have made this point explicit in the discussion section.
Discussion – Social skill..., p26, line 19: may not (just) be due to peers dying around them but due to the shorter trajectory meaning there is less need/seeking of peer support.	Thank you for this point. We agree and have amended accordingly.
Discussion – Social skill..., p26, line 26: not sure about the word “conceal” (although it is in some literature) – it is more about just getting on with life in COPD (“living with” COPD)	<p>In the papers we included, the sense of concealing or hiding both conditions did come through strongly:</p> <p>Having a self-inflicted disease gave rise to self-judgement and shame and participants struggled against being labelled as a COPD patient, partly through hiding and isolating themselves from the outside world. (Lindgren et al, 2014, p.445)</p> <p>The women became outsiders due to the smoking-related disease [COPD] for which no one could be blamed but themselves. One woman experienced herself as a leper when partying. (Jonsdottir & Jonsdottir, 2007, p.299)</p> <p>Thoughts about not being entitled to health care and fear of being identified as a ‘COPD patient’ made participants prepared to forgo further information and treatment: “at the same time, I don’t know, do I dare go there [pulmonary rehabilitation]? Cause then they’ll know...Then I’d actually get the diagnosis, and then it might come out, other people might get to know. ‘Yeah, she’s got COPD!’ [female participant 8] (Lindgren et al, 2014, p.446)</p> <p>Erica’s mother wanted to avoid discussions of her illness [lung cancer] with both family members and other people because she was embarrassed that it was linked to smoking: “I think she was embarrassed that it was lung...She did not want to die of a smoking related illness...we didn’t even get to tell people that she was sick and we had to call and tell them that she died.” (Caughlin, 2011, p.419)</p>

	Relationships with friends were hard to maintain since they did not want them to understand what kind of cancer diagnosis they had... the informants' social activities were limited due to these feelings of shame and guilt (Bertero, 2008, p.864)
Discussion – Social skill..., p26, line 35: not sure “attrition” of social skill and capital is the right term? Rather they have lost opportunities to use their social skill and access capital	Thank you for this point. We agree and have amended accordingly.
Conclusion, p26, line 46: not sure that cancer is the “most dreaded of all diseases” – certainly the most dreaded of the two diseases (COPD and cancer)	We have used Cancer UK’s survey that found a third of people in the UK feared cancer more than any other serious illness http://www.cancerresearchuk.org/about-us/cancer-news/press-release/2011-08-15-people-fear-cancer-more-than-other-serious-illness (see reference 60) but we have modified this statement slightly.
Conclusion, p27, line 27: again, the statement that “a workload which exceeds capacity is likely to be the primary driver of treatment burden” somehow loses the impact of poor understanding of COPD and the differences in the disease trajectories of COPD and lung cancer. I would lean to “...a primary driver”.	Thank you. Amended accordingly
Figure 1a: could this not be prepared for just the COPD papers? Not sure why CKD and CHF are included in the higher rows. I am not following how review papers can be “identified as primary studies” (in one of the cells). Also, no title (needs to say that it is the PRISMA for the COPD literature) and poor quality reproduction.	As the COPD, CKD and CHF searches were done together, we cannot detach the initial COPD, CKD and CHF searches. The review papers were papers that were originally identified as review papers in the main searches. However, when we did the screening of papers, we found 58 papers that were actually primary studies. We agree that this is confusing and have simplified our PRISMA accordingly. We have added a title and redone the PRISMA. Thank you for pointing this out.
Figure 1b: no title (needs to say that it is the PRISMA for the lung cancer literature) and poor quality reproduction.	We have added a title and redone the PRISMA. Thank you for pointing this out.
Table 1: no title.	We have added a title. Thank you for pointing this out.
Table 2: I presume the contents of the two columns to left are from BoT theory and the two on the right are from the findings of the review? If so then the table would benefit from a top row stating this, and also inclusion of reference numbers for the	Thank you. We have amended Table 2 to make this clearer. We have moved psychological co-morbidities to involuntary social isolation.

relevant papers for each item. I also continue to think “Psychological co-morbidities...” should be in “Social isolation (involuntary)” rather than “Social isolation (self-imposed)” – somehow that is even clearer in this table than in the text. It also feels like the physical effects of the condition should be in the “Social isolation (involuntary)” section e.g. breathlessness resulting in houseboundness.	
Title: the term “caregiver” is used throughout the manuscript but “care giver” (two separate words) in the title – suspect this is an oversight.	Thank you for your attention to detail. Changed.
Methods – Treatment..., p9, line 36: delete the hyphen?	Thank you for your attention to detail. Changed.
Methods – COPD as a “way of life” p9, line 54: don’t think “everyday” needs speech marks.	Thank you for your attention to detail. Changed.
Methods – Identifying and accessing treatment options p10, line 27: change the colon to a full stop (suspect there was once a quote here?)	Your suspicion is correct! Thank you for your attention to detail. Changed.
Results – Identifying and accessing treatment options p10, line 50: you have the word “treatment” twice in the sentence – change second one to “them”?	Thank you for your attention to detail. Changed.
Results – Practical workload... p12, line 4: there is a semi-colon that should be a comma	Thank you for your attention to detail. Changed.
Results – Attitude towards treatment – Treatment as work, p13, line 7: “are” should be “were”	Thank you for your attention to detail. Changed.
Results – Attitude towards treatment – Treatment as work, p13, line 12: change the colon to a full stop (suspect there was once a quote here?)	Again, your suspicion is correct. Thank you for your attention to detail. Changed.
Results – Attitude towards treatment – Treatment as a relief, p13, line 31: should “has” be “had” or be deleted?	Thank you for your attention to detail. Deleted.
Results – Attitude towards treatment – Treatment as a relief, p13, line 49: “...than consulting their own preferences” may be better as “...than their own preference”	Thank you for your attention to detail. Changed.
Sometimes “HCP” is used, sometimes “healthcare professional”	Thank you for your attention to detail. We have reviewed and changed all incidences of ‘healthcare professional’ to HCP (apart from the first)
Results – Enacted stigma from healthcare professionals, p21, line 23: comma missing after “COPD” (“... PubMed COPD, experienced....”)	Thank you for your attention to detail. Changed.
The methods section is quite weak through lack of detail. Why just qualitative papers, why not mixed methods? This needs to be	Thank you for this comment. Further detail given.

acknowledged with clear rationale.	
What about grey literature - included/excluded	Thank you for this comment. We did not include grey literature. Explanation of and rationale for given in paper
Quality appraisal of studies is not referred to - this is a central tenant of SR and should be covered in detail in the methods section stating what tool was used, who did the QA and how this was then incorporated into the narrative review.	Thank you for this comment. Further detail given.
How did methods ensure the minimization of errors in regards to data extraction?	Thank you for this comment. Further detail given.
There seem relatively few verbatim extracts for a qualitative review.	Thank you for this point. We were limited by word count and hence were unable to include as many verbatim extracts as we would have wished.
It is usual in SR for inclusion and exclusion criteria to mirror - this is not the case here. Were other systematic reviews included? A full account of the search terms used should be appended, perhaps as an on-line supplement.	Other systematic reviews were not included. We have amended a full account of the search terms as an online supplement.
I found it difficult to follow the overall theme structure and how the proposed grouping of coded data (p8) manifested in the findings. Sub-headings didn't match from the proposed structure to the theme headings. I wonder whether signposting Table 2 earlier (i.e. on p8) would help to clarify this.	Thank you for this helpful suggestion. Table 2 signposted earlier. We have also changed the sub headings.
Some themes, e.g. 'treatment as relief' seem positive, yet negative aspects were also discussed under this sub-heading, e.g. patients report hospital stay as chaotic.	Thank you for pointing this out. We have simplified the sub-headings which should address this issue.
The overall narrative of papers lacks reference to quality appraisal (QA). Without the worth of individual studies' design features it is very difficult to ascertain the findings for quality. Where QA is acknowledged this is superficial and inconsistent	We have given further detail on quality assessment in the methods section.
Overall there are no clear recommendations for policy, practice or research.	Thank you for this helpful point. We have made recommendations for clinical practice.
p7, line 31 - Regarding theoretical approaches there is a need to define 'middle-range' and 'status passage theory'. I	Thank you for this important suggestion. We have defined middle range and status passage theory and given further information on how the framework was

think there is more scope to discuss how the 'framework' was constructed.	constructed.
p20, line 35 - is a reference needed for 'closed awareness context'	Thank you for your attention to detail. We have given a reference for 'closed awareness context'.
p22, line 57: should be many or several conditions, not 'all'	Thank you for your attention to detail. Amended accordingly.
p23, line 9 - May et al 2016 needs Vancouver reference p24, line 10-14 - there is insufficient acknowledgment of limitations, e.g. no mixed methods, no non-English language etc.	Thank you for your attention to detail. Amended accordingly. Further acknowledgement of limitations given.
the abstract refers to eligible papers being from Australia yet Table 1 refers to Australasia.	Thank you for your attention to detail. Amended accordingly.
Better signposting is needed for readers eg. p7 refers to JH who is not on author list so,referring readers to the acknowledgments would be useful at this point.	Thank you for your attention to detail. Amended accordingly.
Appendix 1 is in a tiny font which is not reader friendly.	Thank you for your attention to detail. Amended accordingly.
You present a lot of information with many headings/sub-headings in the main text. This breaks the flow for readers but it's also not always clear when headings are primary or secondary constructs without referring to table 2 e.g. lines 33 and 36 workload and diagnosis are different levels but the text does not differentiate these enough. This means readers are constantly flicking between the text and table to understand what's what. This is especially so the further into the text the reader gets e.g. p16 - line 17 capacity - this needs to be made explicit that this is your 2nd primary construct and how many secondary constructs follow.	Thank you for this comment. We agree with this and have revised the headings to align with table 2. We have also made clear explicitly what headings are primary or secondary constructs.
p16 refers to enhanced capacity following diagnosis, Table 2 refers to enhanced by diagnosis but p8 definition of capacity makes no mention of diagnosis.	Thank you for this comment. We have added in the main text that a finding of the review was that capacity could be both enhanced and/or, paradoxically, diminished by diagnosis.
Other examples of where the text lacks clarity and consistency are Figure 1b needs to refer to lung cancer.	Thank you for your attention to detail. Amended accordingly.
The discussion starts with strengths and limitations but again this creates a disconnect in the flow of the narrative. I would prefer your results led directly to your two final points re: illness as agent and social skill and that this info appeared before your strengths/limitations.	Thank you for your attention to detail. Amended accordingly.
There are many approaches to qualitative	Thank you for this comment. Further details given in

evidence synthesis it is not clear why you decided on this approach. Your approach is novel as you use Shippee's proposition but you do not say much about this (and what you do say is in your results section). There needs to be more detail about what you did e.g. was Shippee used as the explanatory propositions were formulated or was this used later?	methods section.
Did you exclude any studies based on RATS?	We have given further detail on quality assessment in the methods section.
Who checked extracted data for accuracy?	We have given further information on the extraction and coding of data in the methods section.
you replicated and extended a previous search strategy and refers readers to another paper. Detailed info about the search strategy needs included in this paper - readers should not be expected to look elsewhere for that information especially as the first search was for systematic reviews rather primary qualitative studies so you need to make it clear how your extensions here ensured you identified all relevant studies.	We have given further information about this in the methods section and included the MEDLINE search strategy as an appendix.
Your limitations should also consider your QES approach e.g. you had 85 copd and 42 lung cancer studies -did the huge volume of qual data limit your ability to retain conceptual depth? Could you have done something differently e.g. perhaps synthesised the two groups of studies then brought the findings together?	As you point out, there are many approaches to QES. We believe that we took a rigorous approach to analysis and synthesis that did not limit our ability to retain conceptual depth.
How did you ensure reflexivity in your study?	Reflexivity was ongoing throughout the study. First in discussions and reflections on the theoretical coding framework. Second, in discussions and reflections on extracted and coded data. Third in reflections and discussions for the development of the simple explanatory propositions, supporting evidence for these and the development of the taxonomy.

VERSION 2 – REVIEW

REVIEWER	Dr Morag Farquhar University of East Anglia (UEA), Norwich, UK
REVIEW RETURNED	07-Oct-2018
GENERAL COMMENTS	I enjoyed reading your responses to my review (and those of my fellow reviewer), although I am not sure that "colonisation" (as used in your response) is a real word! The paper will be a useful addition to the literature.
REVIEWER	Dr Carol Kelly Edge Hill University, United Kingdom

REVIEW RETURNED	16-Aug-2018
GENERAL COMMENTS	<p>The authors have done a thorough job of revising this piece. They have taken on board all reviewers' comment and this in turn has strengthened the paper. Just a few minor observations from this current review:</p> <p>p6 - the three main concepts for the search strategy are listed but lung cancer is not included here. I wonder given the feature of this disease whether this is an omission. The inclusion of lung cancer is more obvious in Appendix 1 but does appear as an add on. If this was the case and this was an additional search following the original then this should be explicit in the reporting.</p> <p>p6/7 The following sentence appears contradictory: "We looked at primary qualitative studies examining patients with COPD and lung cancer and their informal caregivers' interactions with health and social care, rather than studies which explicitly examine treatment burden in COPD or lung cancer as there are so few." This suggest that the search was for COPD AND lung cancer rather than COPD OR lung cancer, the search strategy and text on methods suggests that co-morbid disease was not included. Further clarification of this issue is needed.</p> <p>The authors' response regarding why they included only qual. papers and no mixed methods stated: "we excluded mixed methods studies as the majority of these studies screened suggested the qualitative components of the studies addressed a very specific research question, meaning that there was little data relevant to our research question." I don't think the answer really highlights the reasons for exclusion, or indeed whether this was an exclusion criteria or the fact that studies were not selected owing to relevance - these are two very different aspects and clarification is needed.</p> <p>When discussing screening and reviews five authors are cited. the paper states that batches of citations and abstracts were screened individually (p7) and then a third reviewer resolved disagreements. I think this needs to read that two reviewers screened batches individually and then disagreements resolved by a third. Likewise with the full text screen - papers were reviewed by disease category independently by one reviewer and then a third resolved disagreements - who was the second reviewer? This needs to be transparent.</p> <p>Finally, I think a table setting out the primary and secondary constructs at the start of the findings section would enhance readability.</p> <p>Overall I think this review offers a novel insight into treatment burden and comparison between disease entities. The authors should be commended for such a thorough piece of work.</p>
REVIEWER	Nicola Ring Edinburgh Napier University, Edinburgh Scotland UK
REVIEW RETURNED	14-Sep-2018

GENERAL COMMENTS	<p>This revised manuscript was so much easier to read than before. As a reader it was relatively easy to engage with your work and findings. Overall, I am satisfied the authors have responded to the issues raised in the initial review although I have 3 minor comments/suggestions:</p> <ul style="list-style-type: none"> - reflexivity in your study - you note in your response to reviewer comments how this was achieved but this information does not appear in your paper. As this is an interpretive synthesis I think it would be useful if you commented on your reflexive processes somewhere in your narrative so, that other readers can see what you did. - the taxonomy - the formatting needs improved e.g. headings do not fit neatly into boxes but this may be improved at the editing stage? - p24 - your statement that lung cancer may not allow time for patients to develop self management techniques. This is true but there may be other reasons too e.g. that patients and caregivers may not see self management in lung cancer as appropriate or possible. Perhaps this sentence could be re-worded?
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VERSION 2 – AUTHOR RESPONSE

Comments	Response
The three main concepts for the search strategy are listed but lung cancer is not included here. I wonder given the feature of this disease whether this is an omission. The inclusion of lung cancer is more obvious in Appendix 1 but does appear as an add on. If this was the case and this was an additional search following the original then this should be explicit in the reporting.	Thank you for this helpful comment. We have amended the reporting to make this explicit as follows: "We initially ran the search based on the above index conditions. We subsequently ran a separate search with lung cancer as the index condition."
The following sentence appears contradictory: "We looked at primary qualitative studies examining patients with COPD and lung cancer and their informal caregivers' interactions with health and social care, rather than studies which explicitly examine treatment burden in COPD or lung cancer as there are so few." This suggest that the search was for COPD AND lung cancer rather than COPD OR lung cancer, the search strategy and text on methods suggests that co-morbid disease was not included. Further clarification of this issue is needed.	Thank you for pointing this out. You are quite right and we have now amended the sentence so it reads "We looked at primary qualitative studies examining patients with COPD or lung cancer"
The authors' response regarding why they included only qual. papers and no mixed methods stated: "we excluded mixed methods studies as the majority of these studies screened suggested the qualitative components of the studies addressed a very specific research question, meaning that there was little data relevant to our research question." I don't think the answer really highlights the reasons for exclusion, or indeed whether this was an exclusion criteria or the fact that studies were not selected owing to relevance - these are two very different aspects and clarification is needed.	Thank you for querying this. We have changed the explanation to "After retrieving and screening full text articles, we decided not to use mixed methods studies as the majority of these studies screened suggested the qualitative components of the studies addressed a very specific research question, meaning that there was little data relevant to our research question."

When discussing screening and reviews five authors are cited. the paper states that batches of citations and abstracts were screened individually (p7) and then a third reviewer resolved disagreements. I think this needs to read that two reviewers screened batches individually and then disagreements resolved by a third. Likewise with the full text screen - papers were reviewed by disease category independently by one reviewer and then a third resolved disagreements - who was the second reviewer? This needs to be transparent.	Thank you for pointing this out. We have amended the methods section to read as follows: KAL, MM, AC and CRM individually screened batches of citations and abstracts to assess eligibility against the inclusion/exclusion criteria. A further reviewer (JH, see acknowledgements) resolved eligibility disagreements at this stage. We obtained studies in full text where it was not immediately possible to determine eligibility against inclusion/exclusion criteria. KAL, MM AND JH independently double screened all full-text COPD articles for eligibility; KAL screened all full-text lung cancer articles for eligibility with 10% of the full text papers screened by CRM. A further reviewer (KH, see acknowledgements) resolved eligibility disputes at this stage.
I think a table setting out the primary and secondary constructs at the start of the findings section would enhance readability.	Thank you for your suggestion. We have included a table as you suggest.
Overall I think this review offers a novel insight into treatment burden and comparison between disease entities. The authors should be commended for such a thorough piece of work.	Thank you for your kind comments. We appreciate the time that you gave to review our paper. The clarity and structure was greatly enhanced by your helpful comments.
This revised manuscript was so much easier to read than before. As a reader it was relatively easy to engage with your work and findings.	Thank you for your kind comments. We appreciate the time that you gave to review our paper. The clarity and structure was greatly enhanced by your helpful comments.
reflexivity in your study - you note in your response to reviewer comments how this was achieved but this information does not appear in your paper. As this is an interpretive synthesis I think it would be useful if you commented on your reflexive processes somewhere in your narrative so, that other readers can see what you did.	Thank you for this suggestion. We have added the following section on reflexivity: "As this was an interpretative synthesis, it was important to ensure that reflexivity was ongoing throughout the study. We did this first through discussions and reflections on the theoretical coding framework. Second, in discussions and reflections on extracted and coded data. Third in reflections and discussions on the development of the simple explanatory propositions, supporting evidence for these and the development of the taxonomy."
the taxonomy - the formatting needs improved e.g. headings do not fit neatly into boxes but this may be improved at the editing stage?	Thank you for pointing this out. We will discuss this with the editorial team and ensure that the formatting is improved.
p24 - your statement that lung cancer may not allow time for patients to develop self management techniques. This is true but there may be other reasons too e.g. that patients and caregivers may not see self management in lung cancer as appropriate or possible. Perhaps this sentence could be re-worded?	Thank you for this helpful comment. We have reworded the sentence to read: "This may be because the short disease trajectory of lung cancer does not allow patients to develop adequate self-management techniques and/or because patients/informal caregivers do not see self-management as appropriate or possible."
I enjoyed reading your responses to my review (and those of my fellow reviewer), although I am not sure that "colonisation" (as used in your response) is a real word! The paper will be a useful addition to the literature.	Thank you for your kind comments. We appreciate the time that you gave to review our paper. The clarity and structure was greatly enhanced by your helpful comments. We are not sure colonisation is a real word either (you won't find it in the paper).

